

Evanston Home Helps Disabled Live On Own

By Lisa Black
Tribune Staff Reporter

After years of caring for their physically and mentally disabled adult son, Sharon and David Campbell were stunned to learn that Rob wasn't eligible for state aid and there was a 10-year waiting list to house him.

With nowhere else to turn, the Waukegan couple took matters into their own hands and joined with other families to house Rob Campbell and five other disabled adults at a red-brick three-flat in Evanston.

It costs the Campbell about \$2,000 a month for housing, staff and support services, but they say it's a price they're willing to pay to ensure their son's care as they grow older.

"In the back of our minds was the question, what will happen when we die?" Sharon Campbell said. "There are very few answers."

Faced with a patchwork social-service system that experts say falls short of providing adequate employment, training, housing and transportation for the disabled, parents such as the Campbells are pioneering a do-it-yourself approach to long-term care for their children.

Some supporters compare the movement to the parent-led push to educate children with disabilities in the 1950s.

Rob Campbell, 40, can drive to his job in Zion at Northpoint Achievement Center for the disabled. But he had lived with his parents all his life, coping with developmental delays and foot deformity. He also was diagnosed with bipolar disorder in the mid-1980's.

The federal Individuals with Disabilities Education Act requires free educational and support services for people younger than 21. But once a disabled child reaches that age, experts say, families are forced to find services on their own, apply for whatever state or federal funding is available and pay the rest them-

selves.

The Evanston Building is the first outgrowth of a non-profit organization called the Center for Independent Futures, which through the efforts of 40 families opened the three-flat in September. The families share a common goal: to help their own children, although many are too young to benefit right away.

The building is home to three men and three women who struggle with disabilities that include autism, bipolar disorder and developmental delays. All pay rent but require financial assistance from their parents.

The three men share the first floor, and the women the second floor. A couple hired as "community builders" live on the top floor in case of emergencies. Each resident has been assigned a personal tutor who helps them achieve goals such as paying bills, balancing a checkbook or improving social skills.

Supporters say it's an innovative approach during a climate of budget cuts and waiting lists. Illinois ranked 47th nationally in 2002 in spending on community services for the disabled, according to a report by the University of Colorado's School of Medicine and Coleman Institute.

"It's people who are pioneering," said Kay Branz, who with another Evanston parent, Jane Doyle, started the Center for Independent Futures four years ago.

Branz's daughter, Elise Hylton, lives in the Evanston three-flat.

"People say, 'You're amazing.' But what choice do we have?" Branz said. "At some point you say, my child and my life is worth this risk, and we have to do it."

But critics say the do-it-yourself approach is too expensive for most families and question who will be held accountable if the privately funded programs are not subject to regulations that apply to government agencies.

The Center for Independent Futures has flexibility in hiring staff and running programs because it does not rely on federal or state funding. State officials say that as long as the families seek guidance

from reputable advocacy organizations, they don't have a problem with it.

Within a few weeks, The Arc of Illinois, a statewide advocacy association for people with disabilities will propose legislation that calls for the state to provide stipends for families for housing arrangements and other services.

"The issue from the perspective of the state is, if taxpayers' dollars are being used, what's the level of accountability?" Said Robert Gettings, executive director of the National Association of State Directors of Developmental Disabilities Services, of Alexandria, VA.

In Illinois, advocates say money is available to support such programs but is largely used instead to maintain institutions rather than help families.

The state spends about \$300 million to house and provide medical services for 2,200 adults in nine state institutions--about \$126,000 per person, according to Department of Human Services.

State-funded group homes house another 7,000 people. The state's cost to operate a group home is about \$45,000 per person, not including medical costs.

While state-funded agencies offer work sites and housing for the disabled, it is often difficult to find an opening that provides an exact fit for what each person needs, said Tony Paulauski, executive director of The Arc.

The state keeps no single waiting list for such housing, forcing families to search on their own for limited options that often are undesirable or far away.

At the Evanston building where Rob Campbell lives, families said they hope to keep costs to \$25,000 a year per person. Besides opening the three-flat, 10 more families have just completed a contract on a second housing arrangement in Evanston. The agreement would provide a place for five men and women to live in apartments next to other non-disabled tenants, in units over a commercial building, Doyle said.

Rob Campbell said he has been happy since moving into the three-flat in northwest Evanston in September.

"It's neat because each have our own

room,” he said. “We have a common room, a dining room, and in the back is a washer and dryer that everybody uses. We have a foosball and air-hockey game. I can walk to the video store. I can ride my bike anywhere I want to.”

His parents say the arrangement has offered their son an extraordinary level of independence, and as a result, he is taking more responsibility for himself.

Said Sharon Campbell: “He wants to live in his own place and travel and do all the things other people do.”